

**PROJECT HOME EVALUATION:**

**FINAL REPORT**

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## **EXECUTIVE SUMMARY**

Project Home, funded by the New York State Department of Health, was an innovative project designed to address the desires of an aging population to receive care in home and community-based settings. Consistent with the public policy goal of diverting individuals away from nursing home care when possible, the project focused on transitioning current nursing home residents to the community. Project Home operated from 2005 to 2009, providing discharge planning services and training and education to area hospital and nursing home staff. During this time period, Project Home staff worked with individuals in nursing home care, helping them to pursue the option of living at home or in an appropriate community setting.

A rigorous, multi-method external evaluation of the project was conducted by researchers from the Cornell Institute for Translational Research on Aging to determine the impact of the program. The evaluation measured specific outcomes relating to participants, including formal and informal support, hospitalizations and emergency department visits, medical history, mental health, cognitive and behavioral health, mobility, use of assistive devices, number of medications, Activities of Daily Living, Instrumental Activities of Daily Living, and quality of life. Data were collected from 60 participants for up to one year as well as from agencies that served clients. In addition, the research team analyzed case notes that were maintained by Project Home staff, which provided a rich source of qualitative data about the barriers and attributes associated with going home or staying in the nursing home.

Results of the quantitative evaluation revealed that Medicaid status was the only statistically differentiating factor between clients who returned to the community and those who remained in long-term care, indicating that, apart from financial resources, transition to the community was possible for all types of clients. Further distinguishing the two groups were the

specifics of their cases, captured by qualitative data in the form of case notes maintained by Project Home staff. The case notes reflect three main themes that complicated many clients' discharge from the nursing home: 1) having an unstable or complex medical condition, 2) lacking family or social support, and 3) being able to obtain suitable housing. The case notes also illustrate the strategies that Project Home staff used to address these barriers, highlighting the strengths of the program. In their knowledge of local resources, role as client advocate, and ability to work with a client over many months, Project Home staff were often able to overcome major obstacles to community living. Overall, Project Home's flexible and goal-orientated approach was central to the success of the program because it transcended many assumptions about client needs, and, in doing so, provided valuable and unique assistance in the transition process.

Finally, information on the cost of care for clients, while somewhat limited, suggest that Project Home clients who transitioned to the community were spending far less money on home care and other services than the cost of the nursing home, and doing so while living in accordance with their wishes.

## **I. INTRODUCTION AND OVERVIEW**

Project Home was funded by the New York State Department of Health and implemented by Loretto. It was designed to be responsive to the desires of an aging population to receive care in home and community-based settings by creating cost-effective changes in the long-term care system. Individuals eligible for Project Home were persons identified as needing (or likely to need) permanent placement in long-term care. Prospective clients were individuals whose physical or mental health problems and/or housing, financial, or other needs made it challenging to create a discharge plan.

In its conceptual basis and design, Project Home was part of a growing movement to transition nursing home residents to other residential situations while maintaining an appropriate level of care. Although screening tools to keep low-need individuals out of nursing homes have become popular in the last two decades, Mor and colleagues estimate that between 5% and 12% of the nation's 1.4 million long stay residents fall into a category of low need<sup>1</sup>. Thus a public policy goal is to divert individuals from nursing home care who do not require it. Support for this movement came from the 1999 Olmstead decision, which requires states to administer programs and services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."<sup>2</sup>

Unlike some other programs that work to divert individuals to home and community-based care prior to institutionalization (for example, after hospitalization), Project Home focused on returning individuals already in the nursing home to the community. Project Home began

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<sup>1</sup> Mor, V., Zinn, J., Gozalo, P., Feng, Z., Intrator, O., & Grabowski, D. C. (2007). Prospects for transferring nursing home residents to the community. *Health Affairs*, 26(6), 1762-1771.

<sup>2</sup> U.S. Department of Health and Human Services. (2009). New Freedom Initiative overview. Retrieved January 6, 2010, from <http://www.cms.hhs.gov/NewFreedomInitiative/>

operating in 2005 and continued into 2009, providing discharge planning services and training and education of area hospital and nursing home staff.<sup>3</sup> The distinguishing hallmark of Project Home was the level of intensity of case management provided; Project Home staff were able to work with clients over many months, assisting them with day-to-day problem solving as needed. Using their in-depth knowledge of community resources and given relatively small caseloads, staff could troubleshoot and advocate for clients to a degree that is unusual in other programs.

This report describes the results of the evaluation of Project Home conducted by the Cornell Institute for Translational Research on Aging. After describing the goals of the project, data are presented on barriers to returning to the community and on resident outcomes in the areas of quality of life and cost.

### *Project Goal*

The ultimate goal of Project Home was to make it possible for Onondaga County residents 65 years of age and older being discharged from a hospital to nursing home care to have the opportunity to pursue the option of living at home or in an appropriate community setting, when such a setting could meet their needs safely and be provided within the limits of available resources. The project anticipated assisting in the discharge of 50 individuals in the first year, adding approximately 50 per year to a maximum of 200 over three years.

### *Structure*

Project staff included a Coordinator, Social Worker, Administrative Assistant and Research Associate. A Community Advisory Committee was formed with representation from area nursing homes, hospitals, and long-term care agencies to provide input and oversight for the project. Project Home staff planned to create an early identification and comprehensive referral

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<sup>3</sup> Project Home also contained a workforce development component that focused on the needs of a home and community-based care workforce. The workforce training component of the project is outside the purview of this evaluation.

and case planning system for hospitalized individuals identified as being in need of nursing home care. As its primary focus, Project Home assisted area nursing homes in effective discharge planning for residents able to and desiring to live in noninstitutional settings.

To better understand barriers to discharge from institutional settings the following evaluation tasks were conducted:

1. An analysis of the barriers that appeared to prevent individuals deemed eligible for Project Home from returning to the community.
2. An examination of differences in outcomes between individuals who returned to the community and those who did not.
3. An analysis of the cost of care for Project Home clients who returned to the community, compared to the average cost of nursing home care in Onondaga County.

## **II. METHODS FOR THE EVALUATION**

Patients at Syracuse-area nursing facilities were referred to Project Home by discharge planners and case managers. Project Home staff marketed their services by distributing printed materials and developing relationships with facility staff throughout the course of the program. Based on the sources of participants, recruitment and referral efforts were the best at Loretto nursing facilities, which provided over 63% of Project Home's clients. In addition, 17% of participants were recruited from Rosewood Heights with the remaining 20% coming from seven other facilities.

When an individual enrolled in the program, Project Home staff collected baseline medical information and completed the Short Portable Mental Status Questionnaire (SPMSQ), a screening tool to detect cognitive impairment. If the client passed the SPMSQ and gave informed consent, he or she was eligible to participate in the program evaluation. The Research Associate contacted the client and scheduled follow-up interviews every 3 months throughout the next year. A complete set of evaluations yielded five surveys (intake, 3 month, 6 month, 9 month, and 12 month). Some clients decided to withdraw from the research portion of the program before the year was finished, and several other clients died before the research could be completed. Project Home enrolled 130 participants, 74 of whom were able to transition to the community. For the remaining 56 clients, discharge from the nursing home was either not feasible, the client disenrolled, or the client died. Of the 74 individuals enrolled in Project Home, 60 agreed to take part in the evaluation.

The survey administered by the Research Associate consisted of several sections of open-ended or scaled response questions on the following topics: formal and informal support, hospitalizations and emergency department visits, medical history, mental health, cognitive and

behavioral health, mobility, use of assistive devices, number of medications, Activities of Daily Living, Instrumental Activities of Daily Living, and quality of life measures. The survey used for client intake was a slightly expanded version of the research questionnaire and collected slightly more personal and medical information, such as religious identification and types of prescription drugs being taken. In both cases information may have been obtained from the client, the client's chart, or staff working with the client.

In addition to the data collected by the Research Associate in ongoing interviews with clients, two other data sources also inform this evaluation. Project Home staff maintained detailed logs of their interactions with clients that were another rich source of information about the program. These case notes were used to understand the specific types of assistance that Project Home provided to clients. The case notes were also analyzed to highlight common issues or sequences of events that acted as barriers preventing clients from returning to community living. Information on the cost of residing in the community after discharge from the nursing home was collected by the Research Associate from agencies that served clients, such as Meals on Wheels and visiting nurse services. Further discussion of the costs and barriers data is provided in following sections of this report.

### *Sample*

The sample for the evaluation consisted of 60 individuals who met the criteria described in the previous section. Of these individuals, 36 were discharged from the nursing home, and 24 others, although determined to be eligible for transition to the community, were not able to be discharged. Characteristics of the study sample are presented in Table 1. The group that returned to the community did not differ significantly from the group that remained in long-term care in terms of gender, education level, race, marital status, and age of clients. The groups also had



similar scores for levels of cognitive function, mobility, quality of life, social support, and depression.

Table 1.

*Characteristics of Project Home Clients in Program Evaluation*

	<b>Returned to the community</b>		<b>Remained in long-term care</b>		Statistic
	N	%	n	%	
<b>Gender</b>					n.s.
Female	24	66.7	18	75	
Male	12	33.3	6	25	
<b>Education</b>					n.s.
High school education or less	26	74.3	17	73.9	
More than high school education	9	25.7	6	26.1	
<b>Race</b>					n.s.
White	30	83.3	18	75	
Non-White	6	16.7	6	25	
<b>Marital Status</b>					n.s.
Married	7	21.9	4	19	
Not married	25	78.1	17	81	
<b>Medicaid</b>					p<.001
Yes	7	19.4	17	70.8	
No	29	80.6	7	29.2	
<b>Age</b>					n.s.
65-69	7	19.4	7	30.4	
70-74	6	16.7	4	17.4	
75-79	7	19.4	6	26.1	
80-84	10	27.8	3	13	
85+	6	16.7	3	13	
	<b>Returned to the community</b>		<b>Remained in long-term care</b>		Statistic
	Mean	SD	Mean	SD	
Cognitive/behavioral status	0.25	0.5	0.3333	0.63702	n.s.
Mobility	1.8611	0.35074	1.9167	0.28233	n.s.
Quality of life	3.3871	0.87389	3.0873	1.06669	n.s.
Social support	1.8871	0.91933	1.9524	0.83524	n.s.
Depression	0.6979	0.85869	0.7417	0.71579	n.s.

In addition to the Project Home clients, initial attempts were made to recruit a comparison group of nursing home residents from Loretto and other facilities in Onondaga County who were not considered to be Project Home eligible (and thus were expected to stay in the nursing home). However, for a variety of reasons these efforts resulted in a small sample of only 16 individuals. One limitation to recruitment of the sample using this method was that many of the residents who were not Project Home eligible had cognitive impairments that limited their capacity to provide informed consent. In addition, it proved to be very time-consuming and difficult to recruit participants from other nursing homes, due to limited cooperation from these facilities. As discussed in the Outcomes section below, we included this comparison group in one analysis, but the size of the group and the differences between it and the Project Home group at baseline made extensive analysis impossible.

### **III. BARRIERS TO RETURNING TO THE COMMUNITY**

Although all clients received the same services from Project Home, some were able to leave the nursing home while others remained in long-term care. A quantitative comparison of the characteristics of these two groups showed no statistically significant differences between the two groups at baseline, with one exception: clients who successfully transitioned to the community were significantly less likely to be receiving Medicaid than clients who remained in long-term care (see Table 1). The issue of availability of personal funds in transitioning to the community is discussed later in this report. On all other variables of interest, no significant variations were found at the time of enrollment between clients who returned home and those that remained in the nursing home. This lack of difference called for an in-depth qualitative analysis to identify key barriers to returning to the community.

Therefore, to better describe and understand the difference between the two groups we analyzed Project Home staff notes for all the clients in the evaluation. A review of these documents by several coders identified specific barriers and more general barrier themes that prevented some clients from returning to the community. The process for determining both the specific and thematic barriers is described further below.

#### *Specific Barriers*

Specific barriers were identified in the case notes by the Research Associate and by the Project Home staff member who generated the case notes. Phrases (e.g., “continues to smoke while using oxygen” or “needs assist of one for all transfers”) were called out in the case notes as being barriers to implementing the discharge plan for the given client. These are very specific issues that were noted by Project Home staff as roadblocks to proceeding with client discharge. The barrier highlighted in the case notes does not in and of itself indicate that it was an

insurmountable obstacle, but rather that the staff member was noting its importance or taking steps to work around the issue. The specific barriers can be divided into the 21 categories listed in Table 2.

Although not all obstacles mentioned in the case notes became major barriers to discharge planning, common wisdom suggests that clients with more recorded barriers would be less likely to transition to a community residential situation. This was in fact not the case. The number of concerns or obstacles reported was not notably different between the group of clients who remained long-term care and the group that moved to other residential settings. Clients averaged between four and five recorded barriers, regardless of whether or not they transitioned to the community, allowing us to conclude that the presence of recorded obstacles does not differentiate the groups.

#### *Most Important Barriers*

Figure 1 shows each barrier as a bar, divided proportionally based on the transition status of clients with this barrier. Note that the degree to which barriers are associated with a client remaining in long-term care differs by the type of obstacle. Some barriers – such as a history of drug or alcohol abuse, housing restrictions, and the need for wound care – are associated mostly with clients who were not able to transition to the community. Other barriers, like an inaccessible home or needing IADL assistance, were listed for 8 and 11 clients, respectively, all but one of whom were able to go home. Although the number of clients with each barrier is too small for conclusive analysis, these data support the idea that some obstacles are more easily overcome by the strategies of Project Home staff and the resources and services in the community.

Table 2

*Examples of Specific Barriers to Discharge Extracted from Case Notes*

Barrier to Discharge	Examples
Agency Refusal/Lack of or Limited Community Resources	denials by home care agencies due to client needs, inability to find appropriate combination of services to meet client needs
Credit Issues or Financial Constraints	client who is homeless, very limited monthly income
Diabetic Needs	sliding scale diabetic with needs for frequent adjusting of injection medication
Dietary Restrictions	renal diet, fluid restriction
Drug/Alcohol Abuse History	history of alcohol abuse while in community
Family Dynamics/Family Unable to Provide Care	no family available, family who is unable or unwilling to provide care
Housing Restrictions	refusals due to medical issues (catheter, colostomy, bed alarm), need for good references when the client lacks them
Inaccessible Home	stairs to bedroom or house, excessive clutter
Lack of Family/Friend Support	no family present, family who is unsupportive of client's goals
Limited Mobility	requiring assistance to transfer, unable to independently move around home
Medical Assessment of Needing 24 Hr Care	medical instruction of needing 24-hour care
Medical Complexity	dialysis, unstable blood pressure, persistent pneumonia, having a feeding tube
Memory Loss/Confusion	too confused to participate in physical therapy, needs cueing to complete tasks
Mental Health Status	anxiety, bipolar disorder, Schizophrenia, behavioral issues that point to undiagnosed mental illness (e.g., hoarding), self-neglect
Multiple Hospital/ED Admissions	multiple recent hospital stays, ED visits after discharge to the community
Need ADL Assistance	needing assistance to dress, needing assistance to use the bathroom
Need IADL Assistance	needing assistance with medication, housekeeping, or grocery shopping
Oxygen Needs	needing to learn to manage oxygen independently
Safety Concerns	concerns from family, housing, or medical staff about client's judgment
Smoking	smoking addiction, client who is smokes while using oxygen
Wound Care	negative pressure wound therapy, chronic and open wounds

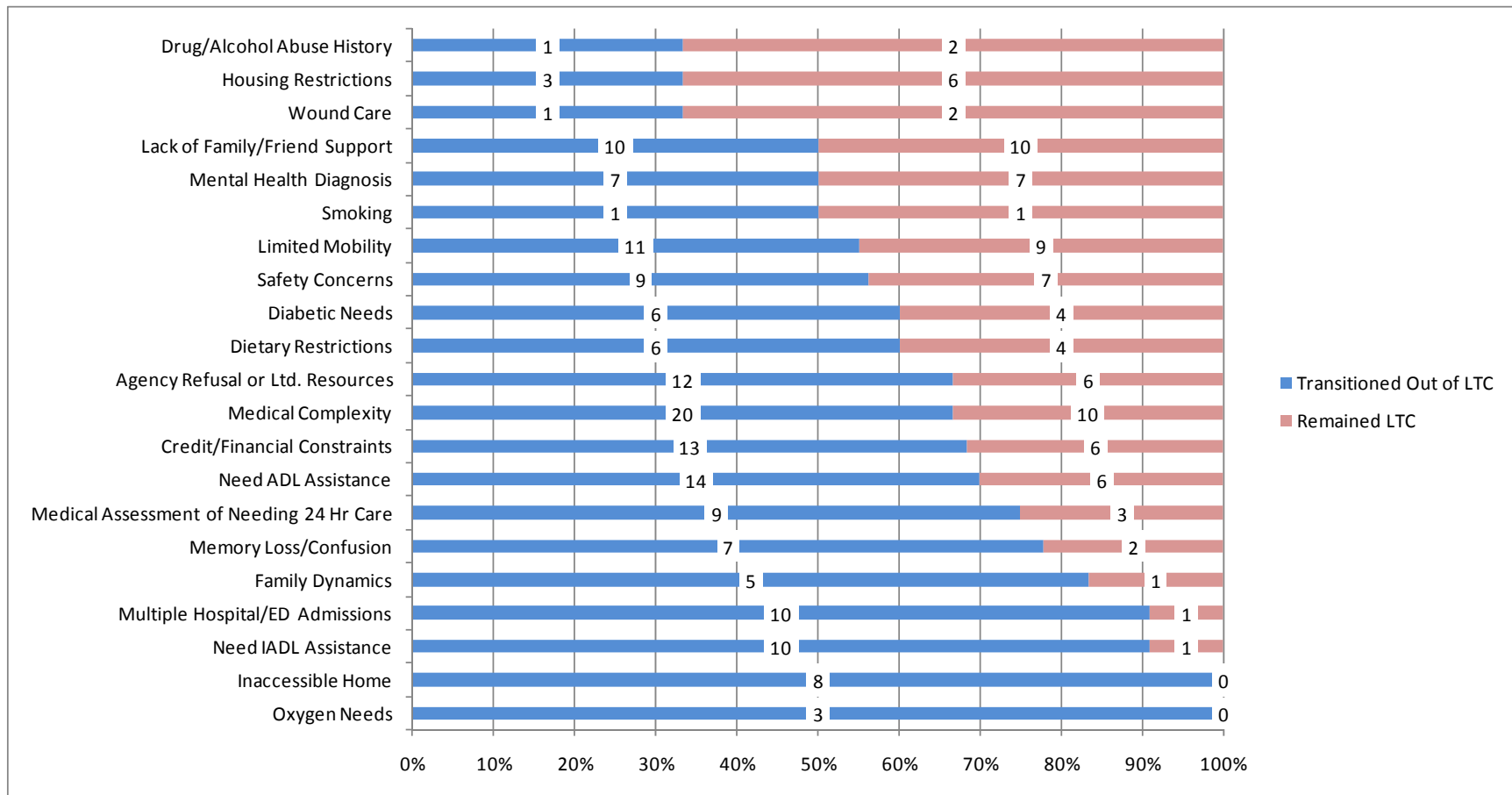


Figure 1. Specific barriers listed in client case notes as they relate to client's ability to transition out of long-term care.

## *Barrier Themes*

Whereas individual occurrences of specific barriers sometimes accurately described the main struggle that clients had, in other cases the overall arc of their stories was not captured by the specific roadblocks itemized by the Project Home staff. Three researchers working on this evaluation reviewed the case notes to identify main themes that summarize the majority of the barriers to community living faced by clients. Three major themes were uncovered: 1) **medical complexity**, 2) **lack of social support**, and 3) **limited housing options**. Each of these categories describes a range of problems that clients encountered. These barriers – alone or in combination – were common across Project Home clients and each triggered particular strategies to overcome them.

### **Medical Complexity**

Many clients were dealing with complex medical problems, overall declining health, or general frailty. When medical issues were understood and under control – diagnosed and successfully managed with medication – even clients with high levels of medical need were able to transition to living situations outside of the nursing home. More difficult cases occurred when the client's health was unstable or when a client had not managed his or her own condition while living in the community previously. In the case of new disabilities or medical equipment, Project Home and nursing home staff used a strategy of building clients' strength, skills, and confidence with managing independently. In some cases, the client's doctor was involved in adjusting the type or dosing of medication or frequency of health monitoring procedures to facilitate the client going home. Another strategy Project Home staff used to accommodate client medical complexity was referral to a residential situation with the capacity to meet the client's medical needs while allowing the client to remain as independent as possible. When medical care was



needed that went beyond the client's ability to manage for himself or herself, Project Home both accommodated this need and continued to plan for discharge.

Several Project Home clients with unstable diabetes experienced difficulty with their discharge plans. From the case notes, clients with high levels of diabetic need had a more difficult time getting accepted by assisted living due to fears that they might become too unstable. The same was true for clients with colostomies or mental health issues: there was an anxiety on the part of assisted living and home care facilities that some future decline would cause the client to go beyond their capacity for care, even though the client was functioning well at the time of application. One such client<sup>4</sup> was receiving injectable insulin four times a day. Unable to manage this medication on his own and unable to secure a position for someone with his level of diabetic need at an assisted living facility, the client remained in the nursing home. After several months his doctor switched him to an oral medication which he needed minimal help to manage, making him eligible for his assisted living facility of choice. Changes in type or frequency of medication or skills around management of medication were crucial to several clients being discharged successfully.

Medical complexity or frailty was sometimes an obstacle that could not be overcome. Sometimes clients' health declined while working with Project Home which then prompted the client to give up on the hope of leaving the nursing home. Other clients were unable to progress in physical therapy as they needed to and limited mobility became the main obstacle to a safe discharge to independent living. One such client had been living independently with in-home services like meals and housekeeping prior to her stay in the nursing home. She became tired quickly and was unable to meet her goal of transferring independently from surface to surface.

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<sup>4</sup> Some details of the cases summarized in this report have been changed to protect the confidentiality of the research subjects.

Although she had hoped to be able to function in her home using a wheelchair, the inability to make progress in physical therapy kept her from realizing hopes of returning home. Not everyone faced such physical obstacles, but some clients were working against the limitations of their health problems and functional limitations, which ultimately caused them to remain in long-term care.

### Lack of Social Support

Lack of social support is generally accepted as increasing one's chances of entering a nursing home.<sup>5</sup> Many clients had no family or friends who were able or willing to assist in discharge planning. For others, issues of distance or health prevented informal support networks from being as supportive as they may have wished. Consequently, Project Home staff provided services to many clients that would normally be provided by informal support, such as assisting with first-time grocery shopping after a client moved to an apartment. The higher level of discharge planning and execution provided by the program, including recommending and negotiating home care services on behalf of the client, is another role that might have been filled by informal support, had capable support been present in the client's life. Within the discharge plan, Project Home suggested the use of formal services to fill these gaps after clients moved to the community. For clients who lacked advocates, Project Home staff also served as an organized and energetic voice, attempting to advance the client's wishes in the face of obvious difficulties.

For clients with low levels of social support, Project Home staff were able to connect and work with friends and family, leveraging whatever support they could offer. One client's son was initially hesitant about the prospects of his father, who recently became wheelchair-dependent,

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<sup>5</sup> Gaugler J. E., Duval S., Anderson K. A., & Kane R. L. (2007). Predicting nursing home admission in the US: A meta-analysis. *BMC Geriatrics*, 7(13).

moving back into the father's previous residence. After Project Home arranged a home visit with the client, physical therapists, and the client's children, the son took charge of making significant home modifications that would allow his father to move about the house safely and easily.

Project Home's focus on problem solving around practical issues reframed a major family health event as a series of tasks that could be assigned and accomplished. Another client had no family present, only an acquaintance at a store she frequented in her town. The acquaintance confessed to Project Home staff that she was not able to continue to be involved in the client's case much longer, as she had family obligations that constrained her time. Project Home staff advised on the most important changes in the client's home that needed to be done which the friend agreed to complete.

There were several cases in which clients' families were unable or unwilling to care for them in the home, which was sometimes the main obstacle to their discharge from the nursing home. One such client's son and his family were living in her home, but seemed resistant to the idea of the client returning home. Because their relationship was strained for several reasons, the client was unable to successfully discharge from the nursing home due to concern about how she would be treated at home, even with paid services in place for nursing care. Another client's wife was open to the idea of him moving home but was unable to provide care due to her work schedule and inability to physically assist her husband in transfers from surface to surface. Her honesty about her ability to participate helped Project Home craft a more realistic discharge plan, albeit one that was unsuccessful due to the client's lack of progress in physical therapy. Although Project Home staff helped marshal informal support when it was limited, there were sometimes extreme limitations that contributed to the client remaining in long-term care.

## Lack of Appropriate Housing

Project Home worked to create and implement realistic discharge plans for nursing home residents. The goal was not necessarily to return to the client's previous residence; the best situation, due to finances, care needs, or ability, was often assisted living of some type. In some cases Project Home helped translate the recommendations of a physical therapist into a list of needed home modifications that a client's family would need to complete before the client could move home. In cases where the client could not be discharged to his or her former residence Project Home staff undertook finding appropriate housing. In practice, this involved many steps, including identifying housing based on the client's medical needs, financial situation, and other factors that might influence eligibility; assisting the client in filling out applications, which often involved obtaining references and tracking down financial documentation; escorting clients to site visits and screenings; and following up on the application process, in which applications were often delayed or misplaced by housing administrators. The process could be onerous even when the client was well-qualified. Clients with mental health diagnoses, catheters or colostomies, bed or chair alarms, and poor credit or references were often refused from multiple residential facilities, leaving little recourse for Project Home staff.

Housing sites and home care agencies are able to accept or select clients based on medical need and whether or not they feel able to care for the client. Consequently, several Project Home clients who were perceived as too "high maintenance" due to personality or mental health issues had difficulty being accepted by housing or home care services. One client was under the care of a psychiatrist for anxiety and other diagnoses. Although the client followed the discharge plan as set forth – attending adult day care programs, receiving personal care, nursing visits, and delivered meals – her anxiety and blood pressure were aggravated when a nurse

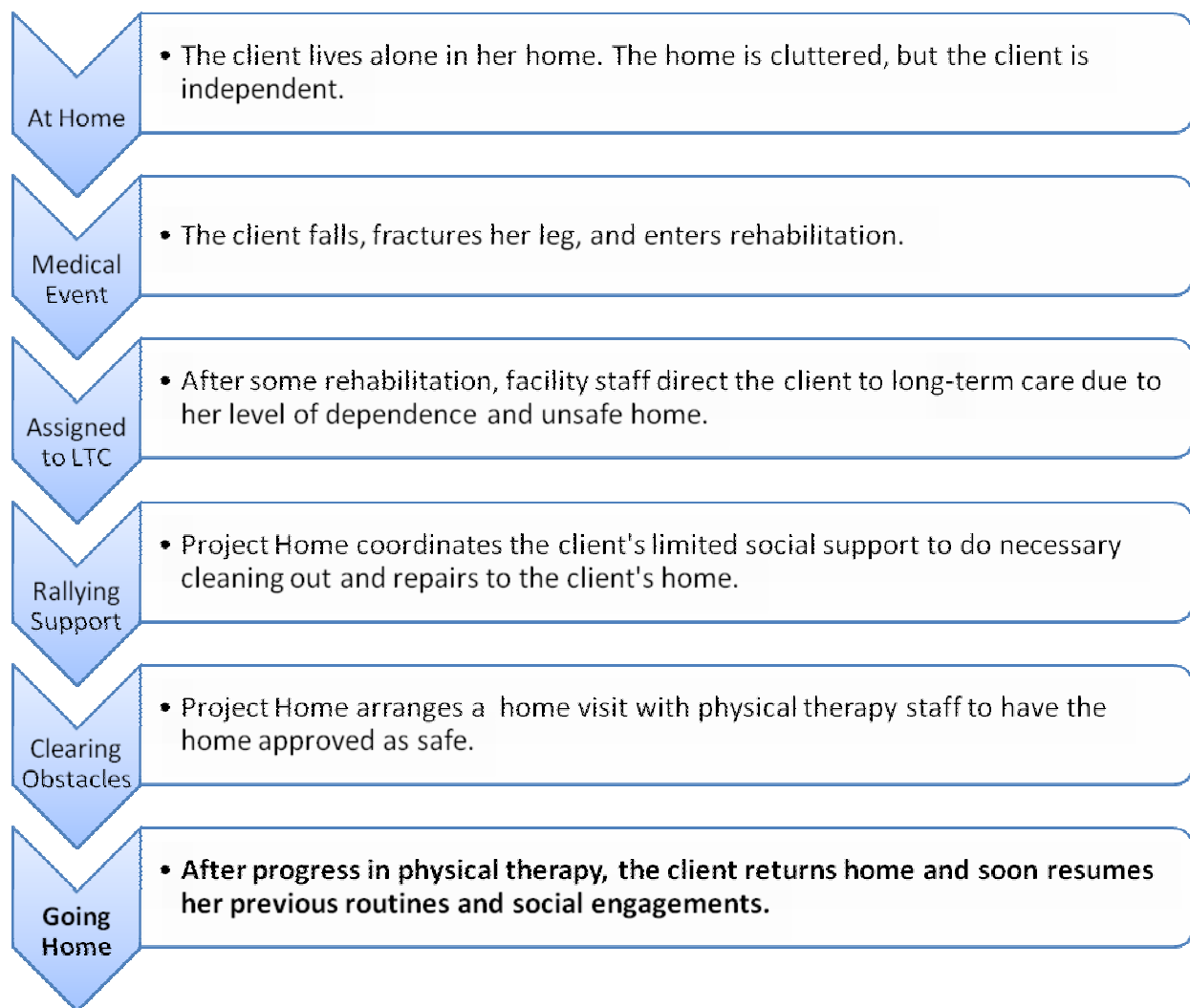
arrived late for an appointment to administer the client's medication to the point of needing to return to the hospital. After difficulty finding a home care service to accept her case for the first discharge, a second discharge to her home was impossible due to the refusal of all local home care agencies to provide services.

Although subsidized housing provided opportunities for several low-income clients to move to the community, there was still an application process that might result in rejection. A new apartment also brought with it the costs setting up a home. Project Home staff helped several clients obtaining furniture for new apartments by soliciting donations from the nursing home staff or apartment building managers. Other clients were unable to work around these obstacles. One client's combined issues of low income, bad credit, and poor references from a previous landlord eliminated every housing option that was pursued. As the client also had no social support and no previous residence, he remained in long-term care even though he was functionally independent and wanted to leave.

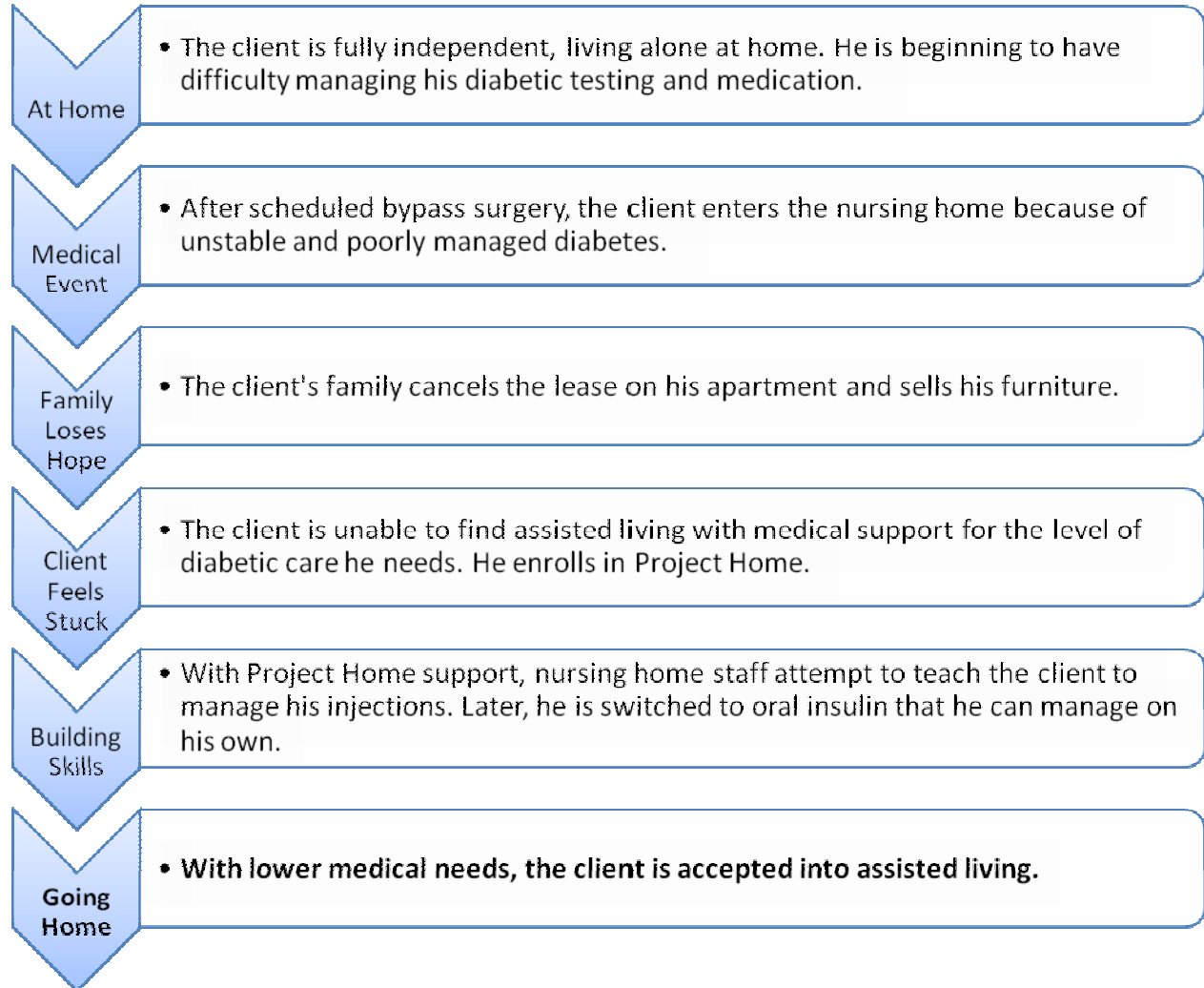
#### *Examples of Barriers and Strategies Used by Project Home*

Figures 2, 3, and 4 provide a graphic illustration of the Project Home process, using three clients as examples. Each figure corresponds to one of the three types of barriers. Figure 2 outlines the course of a client who lacked informal support. In this case, Project Home used a strategy of coordinating limited social resources to solve the problem of the client's unsafe home. Project Home was also a client advocate, requesting and organizing a home visit by the physical therapy staff. The client in Figure 3 was dealing with an unmanaged medical condition that doctors thought would be managed best in long-term care. The client's family resigned themselves to the client not going home, leaving the client without a housing option. Project Home staff worked with nursing home staff to build the client's skills and confidence around

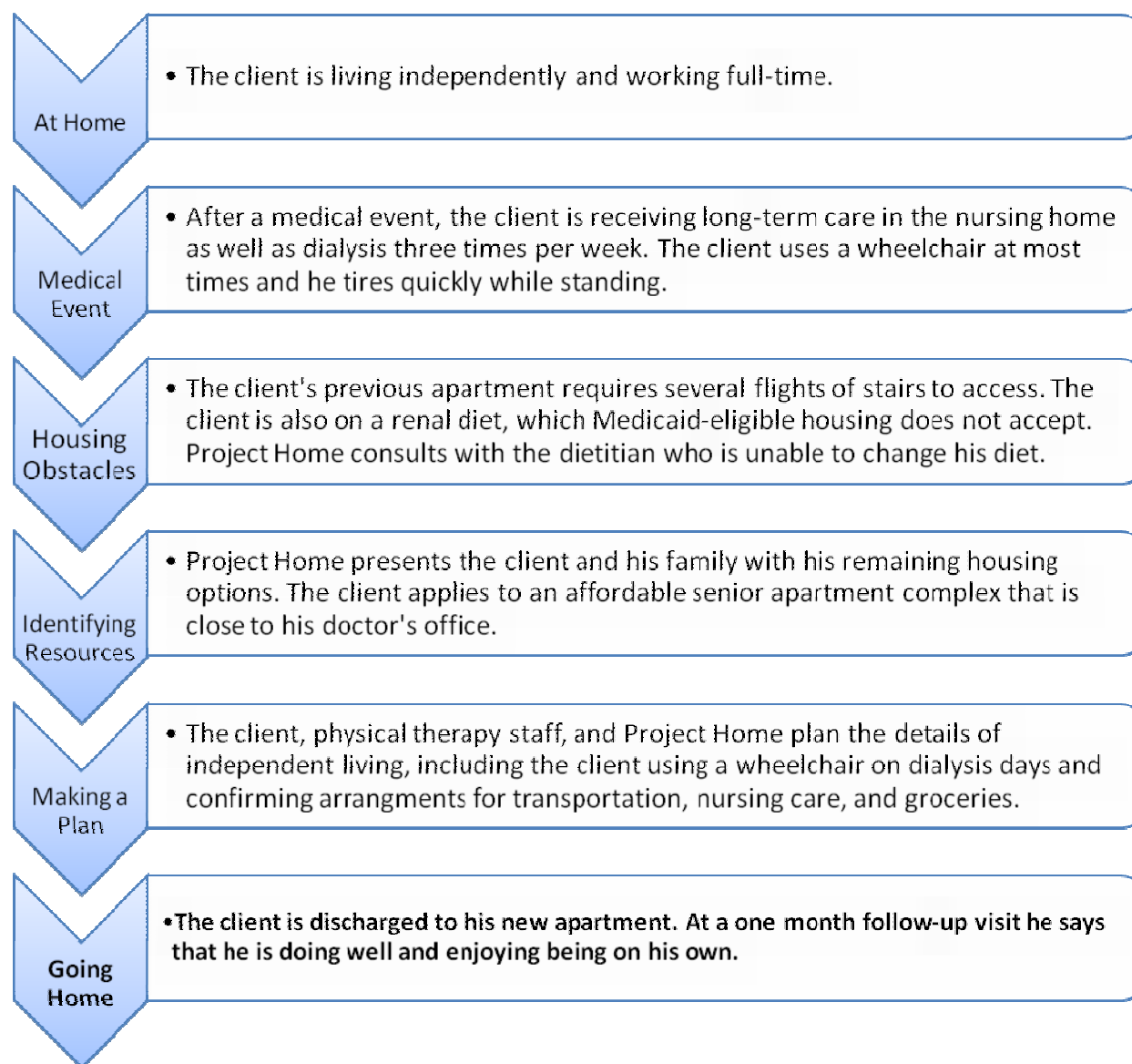
medication management with the goal of the client leaving the nursing home. When the client's medication changed, assisted living became the path to discharge. Figure 4 shows how Project Home helped identify appropriate housing for a client with multiple needs. While the client's limited mobility, weakness, and special diet precluded some housing situations, Project Home provided other options that met the client's needs. Because of the client's high level of need, Project Home also made sure that the discharge plan was acceptable to the client, that he understood it and would comply with it so he could remain in the community safely.



*Figure 2.* Sequence of events experienced by a Project Home client who lacked informal support.



*Figure 3.* Sequence of events experienced by a Project Home client who had a complex medical condition.



*Figure 4.* Sequence of events experienced by a Project Home client who had problems finding housing.

#### *Other Important Barriers*

The major obstacles faced by most Project Home clients fit within one of the three themes above. The case notes of several clients, however, described additional issues that made community placement more difficult, in addition to housing, medical, or informal support needs.



Mental health issues were one such influencing factor. As mentioned above, an official diagnosis of mental illness precluded some housing options. Further, some clients exhibited behavior that might point to undiagnosed conditions, cognitive impairment, or patterns of behavior problems and poor judgment. Although Project Home staff helped these clients with crises as they arose, the one-time interventions were not able to solve chronic problems. For example, Project Home could assist in cleaning out the house of a client who had a problem with hoarding, but the underlying mental health issue could not be addressed. Similarly, Project Home staff could repeatedly discuss the bus schedule with a client who called an ambulance to ask for a ride to the grocery store, but there was also an underlying judgment issue that was beyond the scope of Project Home.

Financial problems were another issue that affected discharge to the community. There are many notes about the expense of home care preoccupying and worrying clients, as well as distressing family members who attempted to cover the cost of home care. Although we cannot be certain about the reason, home care was often reduced or cancelled by clients after they returned home. Clients may have regained independence or switched to an unknown or informal care situation, but some clients worried about cost during one visit and reduced their home care services by the next. Others explicitly state that the level of home care recommended in their discharge plans was too expensive and that they would make do with less. Adult day care programs and the Life Line medical alert service were also turned down by some people due to cost. Additionally, several clients had issues of bad credit or existing debt with the nursing home or home care agencies that prevented them from obtaining housing or being enrolled by home care, preventing their discharge. Finally, we would note that the one statistically significant difference between Project Home clients who did and did not go home was whether they were

Medicaid-eligible, with persons on Medicaid (an indicator of poverty) much less likely to return home. This suggests that limited finances is an important barrier.

Although the barriers that Project Home's clients encountered are, by definition, obstacles to leaving the nursing home, we can take away two positive messages. First, across the 60 Project Home clients in the evaluation, the types of barriers were variations on themes of housing, family or social support, and the level of care needed. The coherence of the obstacles allowed the Project Home staff to become expert at dealing with them. This is especially clear for clients needed housing and home care services: Project Home staff were able to recommend a variety of options based on the client's needs, then use their contacts at these places to monitor the status of applications and intervene as client advocates when needed. The second finding is that some clients had situations or needs that made it much more difficult to leave the nursing home, mostly due to lack of community resources, like assisted living for people with mental illness. This finding indicates that the availability of more community services and creative strategies for nursing home residents with difficult cases could provide additional opportunity for transition to a noninstitutional setting.

## IV. OUTCOMES OF PROJECT HOME

### *Physical and Psychosocial Outcomes*

As noted in the Methods section, Project Home clients were tracked for up to one year to determine changes in a number of variables. It is important to examine possible changes over time for two reasons. First, it is possible that clients who returned to the community derived benefits from the transition. Second, and of greater importance, is to ascertain that individuals who returned to the community did not experience unintended adverse consequences. It is possible, for example, that persons with care needs who return to the community might have worse physical or mental health outcomes, because they are no longer being supervised (and thus miss medications, fail to eat properly, fall, etc.). The most important aspect of the outcomes evaluation, therefore, is to make certain that the group who went back to the community did not fare worse than those who remained in the nursing home.

For these analyses, we used sophisticated statistical methods to examine differences between three groups.<sup>6</sup> For the sake of convenience, we will refer to the Project Home clients who left the nursing home as the “community group,” the Project Home clients who stayed in the nursing home as the “nursing home group,” and the 16 “pure controls” as the “control group.” We were able to compare the community group to both the nursing home group and the control group.

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<sup>6</sup> Analyses were carried out in general linear mixed models. The primary model for evaluation of the intervention was a  $3 \times 2$  repeated measures design (Treatment  $\times$  Time), with treatment and time included as levels of fixed classification factors and individuals included as levels of a random factor. The model also included the treatment  $\times$  time interaction and gender, age, and cognitive status of the resident. The key test in the examination of intervention effects is the test of the interaction of the factors for treatment and time. We examined a primary contrast between the controls and the 2 intervention groups (did and did not go home) combined; we also examined a contrast between controls and the intervention group of residents who went home and a contrast between the 2 intervention groups. We also examined models contrasting baseline and alternative follow-up points (3, 6, 9, and 12 months) and models with a 5-level factor for time. Growth curve models were also tested. In these models the regressions of outcomes on time (5 time points) were specified separately for levels of treatment and the homogeneity of these regressions tested. Both linear and curvilinear regressions were tested.

We compared the community group to the two other groups on the following pre-specified variables: depression, IADL, social support, quality of life, and number of medications taken. It is plausible that any of these variables could have been affected by discharge to the community. In these analyses, we controlled for gender of the client, age, and level of cognitive impairment. In all the analyses, there were no significant differences; that is, over time, the group who returned to the community did not differ from the nursing home group or the control group. In part this may be due to the small sample size, which makes it difficult to detect statistical significance. However, it does appear that there were no negative effects for individuals on any of the variables of interest over time, suggesting that interventions like Project Home do not provide risks for older people.

#### *Cost*

The original proposal to evaluate Project Home included cost savings as a second type of outcome in addition to participant well-being. Significant challenges were encountered in collecting the cost data, which greatly limits the information available for the analysis. For this reason, the data on cost cannot be seen as definitive, and caution is necessary in interpreting the findings and generalizing from them. In this section we detail the issues around the cost data and our findings for selected clients.

Of the 60 Project Home clients in the evaluation, 36 were transitioned from long-term care facilities to a noninstitutional housing situation. Because the discharge plans for these 36 were largely designed by the staff of Project Home, we knew the vendors with whom clients contracted for supportive services, including home care, nutrition (i.e. delivered meals), adult day care, and medical transportation. With the participants' consent, we solicited data from these vendors in an attempt to measure the cost and volume of services used while clients were living

in the community. The categories of costs that we attempted to collect are as follows: home care (including physical therapy, occupational therapy, nursing, companion service, and home health aides), adult day care, nutrition (i.e., Meals on Wheels), durable medical equipment, medical alert systems, transportation, and primary care physician visits. To calculate the cost of care while residing outside of the nursing home, the quantity of services recorded was multiplied by the Medicaid reimbursement rate for each service and summed for each client.

### Home Care

Home care services were a main tool used in discharge planning; to live safely in the community, many clients needed appropriate in-home medical and personal care. Clients were connected with one of five home care agencies, depending on their residence and the type and frequency of services they required. The Project Home Research Associate sent the list of client names to these agencies several times over the evaluation period to request a report of their use of services. All five agencies were responsive to the request and our data for this area is more complete than in others. One complicating issue is that it was not always clear what home care agency clients were using, if any, and our census of agencies may omit formal care services that were being purchased. Clients sometimes had several active home care services at once and at other times switched to an unknown service, discontinued service, or hired neighbors or friends to perform care. It is impossible to disambiguate lack of home care from home care that was sourced through another outlet. We have records of home care costs for 24 participants, although case notes show that additional clients were hiring or receiving paid care from other sources. Where the case notes were consistent with the home care services fees, we considered the home care data complete and included it in the estimated cost of care while in the community.

### Adult Day Care

Only two participants made use of adult day care programs after transitioning to community housing. We have the number of days that each participated and included the cost to each client in the cost of care estimate.

### Meals On Wheels

Meals on Wheels provided the start date, end date, and frequency with which meals were delivered. Each client received two meals per delivery day. Because only seven of 36 Project Home clients received this service, some for very brief periods of time, the cost of meals is not included in the estimated cost of care while in the community.

### Durable Medical Equipment

Most of the durable medical equipment (e.g., wheelchair, walker, shower bench, commode, etc.) that clients used while in long-term care was leased from Loretto. Loretto provided a list of the durable medical equipment that was being used by each client while at home. We do not know what assistive devices people may have bought or owned previously. The costs related to this equipment were estimated to be negligible for nearly all participants and were not included in the cost of care estimates.

### Medical Alert Systems

We collected data on whether or not participants who moved home had medical alert system services (e.g., Life Line, etc.), but the variety of circumstances across clients complicates the calculation of its cost. Some participants moved into housing that included this service. Others already had it in their home. Depending on an individual's situation, the fee on some forms of this service may have been waived by the provider. This cost was not included in estimating cost of care while in the community.

## Transportation

We attempted to collect the costs associated with medical transportation, defined here as ambulance transportation to the emergency department. The medical transport services that clients used most either lacked the recordkeeping systems or the administrative ability to share the clients' costs with us. Other transportation costs (e.g., Call-A-Bus, public paratransit) were not tracked. Transportation costs were not included in estimating cost of care while in the community.

## Primary Care Physician

Obtaining any information from primary care physicians was impossible. The main barrier was physicians' offices' concern about HIPAA privacy obligations. The Project Home program and evaluation consent forms did not meet the HIPAA requirements for disclosing patient data. Cost of primary medical care was not included in estimating cost of care while in the community.

## Other Costs

Though these categories attempt to capture most of a community-dwelling individual's costs, several significant living expenses were omitted. Categories of missing cost data include housing costs, expenditures on home modifications, non-medical transportation, chore or housekeeping services, home or personal care that were not hired through the common agencies, and over-the-counter medication and supplies.

The most significant of these is housing costs. Many clients moved back into their own residences which they owned or rented. Some returned to live with spouses who would have retained the housing situation regardless of the client's residence while others moved in with children. Some clients moved into assisted living, either government subsidized or private

market, which may or may not have come with a range of services attached, from transportation to case management to meals. We have no way of knowing what any client was paying in rent or mortgage and what services he or she was receiving as part of that cost.

Due to these combined limitations, the cost data are sufficiently extensive to report on for only 19 clients, about half of the individuals who went home and who participated in the outcome evaluation. Further, as noted in our discussion above, the data are not complete even for these clients. Therefore, it is impossible to make definitive claims about the cost-benefit relationship of Project Home clients' care at home to institutional care. With that caution in mind, Figure 5 presents data on 18 clients on whom sufficient data were collected.<sup>7</sup> In all of these we feel confident that less money was spent to maintain the client outside of the nursing home.

Even assuming that our scope of expenses is too small and our data collection was incomplete, most clients were spending far less to live at home than the \$186 per day that is the average charge to Medicaid for nursing home care, or approximately \$68,000 annually. As Figure 5 shows, the highest annualized cost for a client was about \$25,000, and the remainder were much lower. It is important to consider that even nursing home residents who pay privately are very likely to transition to Medicaid eventually. Every client's need for home care is different and each client had different material and social resources available to him or her. For all but the highest-need clients, however, we are reasonably confident that the community services as

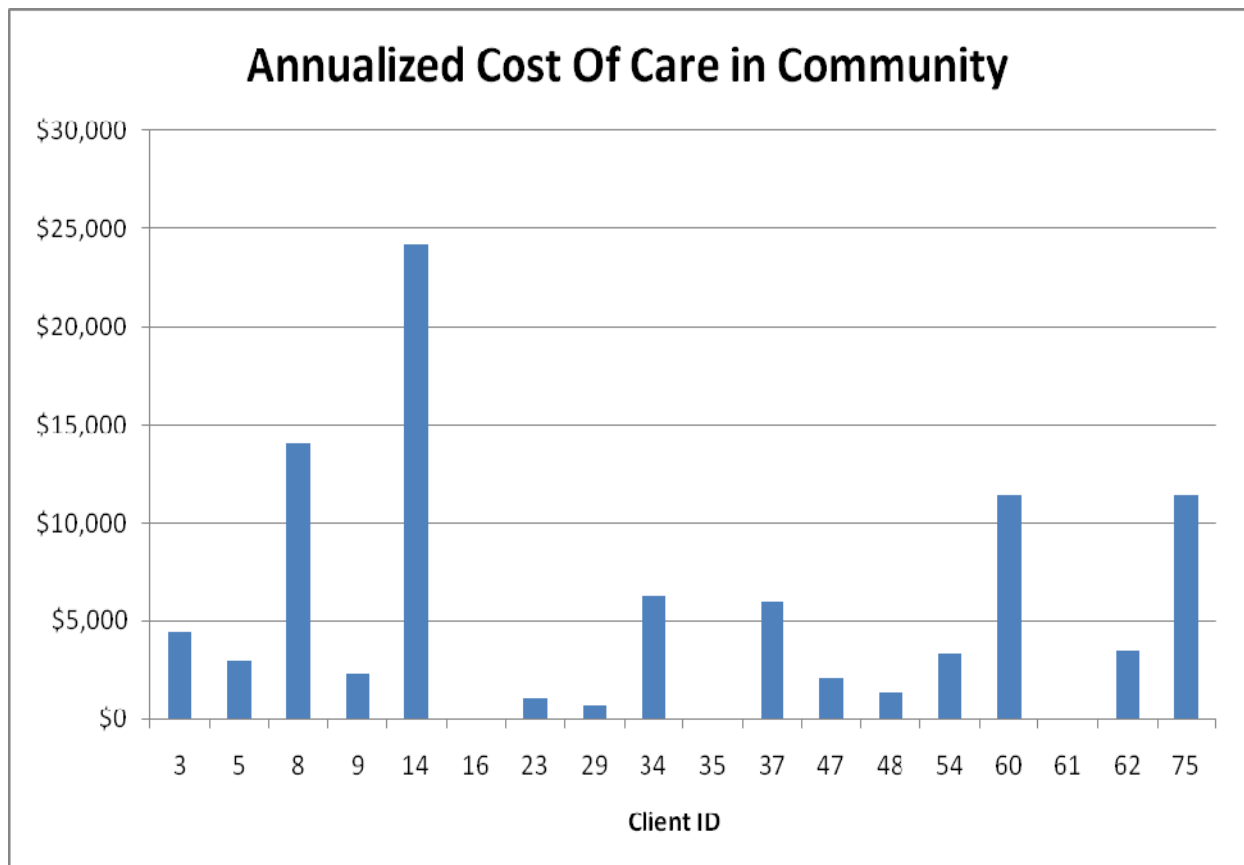
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<sup>7</sup> One Project Home client required 24-hour nursing care but had personal resources to support the cost of care and was very motivated to return home for what the client believed to be, and what were, final weeks before passing away. Annualized, this would lead to extremely high costs for care at home -- over \$500,000 -- so this unique outlying individual was not included in the calculations. Client 16, Client 35, and Client 61 all received no formal (paid) services of the types we collected after leaving the nursing home. The missing bars on the graph indicate zero dollars.



stipulated by Project Home's discharge plans require much less public cost than remaining in long-term care.

*Figure 5.* Annualized cost of care while in community for selected Project Home clients for whom comprehensive cost data were collected.



## **V. CONCLUSIONS AND RECOMMENDATIONS**

This evaluation is based on extensive information that was collected about residents in nursing homes who became part of the Project Home intervention. The data collected on clients ranged from health status to social networks to emotional well-being. These data were collected to explore the hypothesis that there may be some significant difference in the profile of older adults who remain in long-term care facilities compared to those who are able to return to the community. The only significant difference between these groups, however, had to do with their financial status – whether or not they were receiving Medicaid. The qualitative analysis of the barriers to a successful discharge from long-term care revealed further distinctions, with some specific obstacles rather than social or functional characteristics indicating differences between the two groups.

The differentiating factor of Medicaid status is not surprising, as it may indicate pre-existing low income or previous costly medical issues that forced the client to move to a nursing home. Project Home was not specifically equipped to deal with very low income clients. They had no funds at their disposal and, as far as we know, did not utilize Medicaid home and community based services vouchers or waivers. A recommended extension of this intervention would be an enhanced discharge planning service targeted at long-term care residents who are receiving Medicaid that could specialize in voucher and subsidy programs to help make a community living situation possible. The Project Home intervention demonstrates that strategies can be developed to overcome key barriers to returning to the community. If poverty were a central issue in a future iteration of the program, the same expertise and creative problem solving that were demonstrated in Project Home could be used in this new context.

As Medicaid status was the only statistically differentiating factor between clients who returned to the community and those who remained in long-term care, we should note that functional status, social characteristics, and emotional well-being were *not* statistically significant. This indicates that, apart from financial resources, transition to the community was possible for all types of clients and had no negative effects on them. Having a higher documented need for IADLs than another client, being older or younger, taking more or fewer medications, and other factors did not statistically affect a client's chances of going home. For clients who went home, there were no observable declines in health after the move. This is hopeful for people with functional disabilities and serious health problems. It is also indicative of the range and scale of barriers that Project Home staff and community resources were able to address.

The case notes maintained by Project Home staff were an invaluable account of obstacles faced by clients and the types of services Project Home staff provided. These accounts vouch for the expert advice, realistic perspective, and flexible services that the program made available to its clients. In the absence of strong social support, Project Home workers served as client advocates. Even when supportive family members were involved, the presence of Project Home staff seemed to give a boost of confidence to the client, medical staff, or family who may have feared that leaving the nursing home was impossible. Moreover, their knowledge of the transition process and network of contacts at housing and home care services helped streamline and simplify new and often confusing information that clients and families were confronting for the first time.

Although the majority of cases required using one of several familiar strategies, Project Home staff often provided unconventional but undoubtedly helpful services to clients, such as

helping arrange furniture in a new apartment or bringing donated clothes to a client who had too few. This flexibility and goal-orientation was central to the success of the program. Future programs should note this finding. Becoming too set in official strategies or assumptions about client needs, though well intentioned, might have the effect of depriving clients of whatever assistance they might need in the transition process, as unique as it may be.

From what we can tell, sometimes discharge was not the right health choice for the client. In other cases, discharge was not possible due to lack of community resources. Project Home staff formed strategies out of the resources that were available, but when the community lacked resources, such as housing or home care for people with mental health issues, there was little they could do. The trials faced by some clients, and by Project Home staff in their effort to help them, indicate the need for a wider range of supportive housing options for older adults with some medical needs but who clearly do not need to be in high-care facilities. More housing options outside of the nursing home for clients with financial problems, mental health, and substance abuse issues are also needed.

Finally, information on cost of care for clients while residing in the community was collected in the interest of determining savings, if any, over institutional care. Despite the shortcomings of the cost data discussed above, Project Home clients who transitioned to the community spent far less money on home care and other services than the cost of the nursing home, and doing so while living in accordance with their wishes. Most clients who went home were paying privately for their home care, thereby not incurring public cost, whereas continuing in long-term care would have triggered most to apply for Medicaid eventually. Clients who were receiving Medicaid already certainly demonstrated immediate cost-savings for the public. Determining whether or not the program costs of administering an enhanced discharge planning

service like Project Home would ultimately be self-sustaining by offsetting public costs of long-term care is beyond the scope of this evaluation. Given that Project Home successfully transitioned to lower levels of care, with no ill effect, over half of these disabled, older nursing homes residents who had been deemed in need of long-term care, the potential of this type of program to be cost-effective seems plausible.